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ABSTRACT

"Work incentives" encourage and support individuals with disabilities in their efforts to seek employment and have been formalized in federal legislation and regulations, including the Ticket to Work and Work Incentives Improvement Act (TWWIIA). In October 2000, Utah received a 4-year federal grant to change the state's systems of work incentives and supports for individuals with significant disabilities, particularly those receiving Social Security benefits. A major effort under this grant involves providing consumers, state agency staff, and service providers with training and practical knowledge about the new Social Security and Medicaid work incentives authorized under TWWIIA. This training is particularly important in rural areas, where individuals with disabilities are impeded from work by fewer employment opportunities, lack of services and supports, and lack of transportation. This article describes the new work incentives resulting from TWWIIA, as well as previously existing Social Security incentives. Although presented with examples from rural Utah, most information is applicable nationwide. Sections cover Benefits Planning Assistance and Outreach, expanded Medicaid health coverage (Medicaid Work Incentive), Employment Related Personal Assistance, Ticket to Work, protection and advocacy systems, Plan for Achieving Self Support, Student Earned Income Exclusion, Impairment Related Work Expense, and "subsidies" to increase beneficiaries' monthly earnings while not reducing Social Security benefits. (SV)

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WORK INCENTIVES AND THE TRANSITION TO WORK IN RURAL AREAS

Introduction

Over the past several years numerous programs have been designed to provide individuals with disabilities with "work incentives" to encourage and support them in their efforts to seek employment. Many of these "work incentives" have been formalized in federal legislation and regulations including the Americans with Disabilities Act, the Workforce Investment Act, and the Ticket to Work and Work Incentives Improvement Act (TWWIIA).

In October 2000, Utah received a time-limited (4 years) systems change grant designed to improve employment outcomes for individuals with significant disabilities (particularly those receiving benefits from the Social Security Administration) by changing the systems of work incentives and supports in Utah. As part of this grant a group of consumers, family members, state agencies, and private service providers came together to develop the Utah Work Incentive Coalition. This statewide coalition coordinates and administers a number of systems change projects and programs under the umbrella of the Utah Work Incentive Initiative (UWIN).

One of the main UWIN efforts involves providing consumers, families, state agency staff, and private service providers with training and practical knowledge regarding the new Social Security and Medicaid work incentives authorized under TWWIIA. The training is designed to assist Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) beneficiaries, and those who support these individuals, to make informed decisions about entering (or re-entering) the workforce. It is imperative that these individuals fully understand the available work incentives and how to utilize them. A concerted effort has been made to provide UWIN training to individuals, family members and service providers in rural areas of the state, taking into consideration the unique challenges associated with living in rural environments. Additionally, Transition Coordinators statewide have been and continue to be among the key service providers specifically targeted to receive the UWIN training.

Although this article draws upon experiences and information originally developed for Utah, the majority of the information regarding the new work incentives available as a result of the TWWIIA legislation, as well as previously existing Social Security work incentives, is applicable nationwide. Accurate information about these work incentives is critical for individuals receiving SSI and/or SSDI, their families, and school personnel in order to develop a transition plan that will allow individuals to participate in the workforce (or obtain further preparatory education and/or training) to the greatest extent possible. The specific work incentives, which will be discussed in this article include:

- Benefits Planning Assistance and Outreach (BPAO); Expanded Medicaid Health Coverage; Employment Related Personal Assistance Services; Ticket to Work; Protection and Advocacy; and existing SSA work incentives including Plans for Achieving Self Support (PASS), Student Earned Income Exclusion, Impairment Related Work Expense (IRWE), and Subsidy

Why Work

Before discussing the specifics of work incentives it is important to establish a broader understanding of why a transition student receiving Social Security benefits would want to begin to work and possibly reduce or eliminate these benefits completely. What are the benefits of work? In rural focus groups and training sessions across Utah during the past year, young adults and adults with disabilities have been asked to discuss what the benefits of work are and why someone with a disability would want to work. The benefits of working as stated by these participants included increased self-esteem, a sense of accomplishment, opportunities for friendships, being able to contribute to society, the chance to focus on ability and not disability, the chance to "fit in," to be a more active member in society, and greater financial freedom.

Barriers to Work

The follow-up question to "why work?" posed to focus group and training participants was, "If there are so many positive aspects associated with working, why aren't more individuals receiving SSI and/or SSDI working? What are the real and/or perceived barriers to employment that students in transition, especially in rural areas, face?"

According to these rural focus groups as well as training participants, barriers to work for individuals with disabilities include: the fear of losing the safety net of Social Security benefits (for both individuals and families), concern about losing Medicaid benefits, employer discrimination, and the lack of necessary support to gain and maintain employment. These complex barriers to work are further compounded by additional factors associated with living in rural areas. Rural areas generally have fewer employment opportunities overall. There is often a lack of state/private provider services and supports to assist individuals with disabilities enter or re-enter the workforce in these areas. Access to transportation to get to a job is also often problematic (National Organization On Disability [NOD], 2003; Research and Training Center on Rural Rehabilitation [RTC], 2003). All of these challenges suggest that it is even more important for individuals with disabilities in rural areas, and those who support them, to fully understand the variety of work incentives that are available to assist them in overcoming barriers and experience the benefits of work.

Ticket to Work and Work Incentive Improvement Act

TWWIA is designed to increase the employment of people with disabilities nationwide by providing additional work incentives that address some of the barriers previously mentioned. Additionally, as a result of TWWIA, a renewed effort to educate individuals about previously existing work incentives has taken place. These new and existing work incentives are designed specifically for beneficiaries of SSI and SSDI between the ages of 18-64. The two major parts of the TWWIA legislation are the creation of the Ticket to Work program administered by SSA and other efforts to expand health care coverage so that individuals with disabilities can be employed without immediately losing their health insurance (one of the most commonly identified barriers to work by individuals and families) (U.S. Department of Labor, Office of Disability Employment Policy [DOL], 2003).

New Work Incentives

In the following sections, these new incentives are briefly described with an emphasis on their relevance for transition students in rural areas. It is important to note that not all available SSA work incentives are discussed and not all work incentives will apply to all SSI and/or SSDI beneficiaries. The Social Security Administration remains the sole source for official information regarding each applicable work incentive. The purpose of this article is to give interested individuals a brief glimpse of new and existing work incentives that can help students in rural areas who are beneficiaries of SSI and/ or SSDI to transition more successfully into the world of work.

Benefits Planning Assistance and Outreach-BPAO

Benefits Planning Assistance and Outreach (BPAO) is critical to the successful utilization of the new work incentives as well as assisting individuals and families to better understand and utilize an array of existing work incentives. Under the TWWIA legislation SSA awarded every State, the District of Columbia, and the U.S. Territories at least one BPAO project (state specific contact information can be found on-line at www.ssa.gov/work/ServiceProviders).

These BPAO projects are designed to provide all SSI/SSDI beneficiaries, including transition-to-work aged youth over 18, with access to benefits planning and assistance. The role of Benefits Specialists in these programs is to provide individuals, families, and other support providers with a comprehensive analysis of how employment will affect an individual's entire benefits package, including SSI/SSDI cash benefits, health benefits, and other state specific benefits such as food stamps, public housing, and transportation (Social Security Administration, Office of Employment Support Programs [SSA], 2003). With accurate information, transition students can make informed decisions about working. Benefits Specialists also conduct outreach and work closely with Federal, State, private providers, and nonprofit organizations that serve SSI/SSDI beneficiaries to provide assistance to as many beneficiaries as possible (SSA, 2003). Some states have been working closely with transition personnel in the school districts and innovative procedures include meetings with a trained Benefits Specialist to provide a benefits plan as an integral part of the transition planning process. The goal of providing all students receiving SSI/SDI with a comprehensive benefits analysis prior to their leaving the school system is being addressed within several states and at the national level.

This collaboration between the school districts and state BPAO projects is particularly useful in rural districts. In rural and frontier counties, with scarce services and limited systematic access to state level experts, it is imperative that accurate and timely information be available to ensure that informed decisions can be made. For instance, in many rural areas direct person-to-person access to agency personnel, such as vocational rehabilitation counselors, Medicaid eligibility specialists, and/or Social Security representatives may be severely limited. These staff maybe available on an infrequent basis (once a month, two mornings a week, etc.) or may be housed in distant areas of the county or in other counties. Since it is critical for transition students, their families and support systems to have multiple opportunities to explore the impact of working on benefits, the role of the BPAO projects cannot be over-emphasized. In Utah, the BPAO Specialists take applications statewide, and then travel to rural areas to meet personally with interested persons.

Expanded Medicaid Health Coverage (Medicaid Work Incentive)

TWWIIA legislation also provided states with the *option* of expanding Medicaid coverage to people with disabilities ages 18-64 who are employed and have countable income above 100% of poverty. A similar option was made available to states in the Balanced Budget Act of 1997. To date, 26 states have expanded health coverage under one of these options. Under this new option states can increase the income and asset limits for Medicaid eligibility. Individuals making over 100% of poverty (may differ in other states) would be allowed to buy-in to Medicaid by paying a monthly premium based on their income level (DOL, 2003). This buy-in option would allow transition students (over 18 and receiving benefits as an adult) to be employed and continue to receive Medicaid coverage. States have also been given the option to "provide employed individuals who have certain medically determined impairments, as determined by the Secretary of Health and Human Services, the opportunity to buy into Medicaid even though they are no longer eligible for SSDI or SSI disability due to medical improvement" (SSA, 2002, p.3) Additionally, under this expanded health coverage option of TWWIIA, "Medicare's Part A premium-free hospital insurance coverage is extended a minimum of eight and a half years to most SSDI beneficiaries who work" (SSA, 2002, p.3).

Employment Related Personal Assistance (E-PAS)

Employment Related Personal Assistance (E-PAS) is not a specific SSA work incentive, but rather a type of program that several states are developing as part of their recently awarded Medicaid Infrastructure Grants. E-PAS (may be called by different names in other participating states) is a Medicaid service with a general purpose of providing individuals with disabilities personal assistance services to help them maintain employment. In Utah, E-PAS is designed to assist individuals with moderate to severe levels of disabilities to work in integrated settings by providing employment related *direct assistance or cueing* with hygiene, meal preparation, shopping, transportation, etc. Services can be provided at home and/or at work.

It is important to highlight the fact that E-PAS is not limited to *direct physical assistance* with activities of daily living such as bathing, dressing, eating, etc. but also includes *cueing*. Cueing is the type of assistance that individuals with mental illness or cognitive impairments may need in order to remember to take medications, dress appropriately for work, and maintain an employment schedule. In Utah, the E-PAS program will pay for the cost of

a personal assistant's time in transporting an individual to and from their place of employment. This is especially helpful in rural areas where transportation options are severely limited (NOD, 2003; RTC, 2003). It should be emphasized that E-PAS is not the same as job coaching or non-work related personal assistance. E-pas is designed to support individuals who have employment and the corresponding job skills already in place, but require assistance to maintain that employment.

Ticket to Work

As mentioned earlier, the Ticket to Work program is one of the main pieces of the TWWIA legislation. It is designed to provide beneficiaries of SSI and/or SSDI with expanded access to employment services including job training, vocational rehabilitation and employment placement services. This will be accomplished through the establishment of new Employment Networks (EN) in each state. Employment Networks are public or private entities that have received SSA approval to provide job training, employment services, and other related support services to assist individuals with disabilities to become employed. (State Vocational Rehabilitation agencies will automatically be considered an EN). Employment Networks will be compensated based on their ability to assist Ticket holders to become employed and gradually move off benefits. As the number of ENs increases, beneficiaries will be able to choose to receive services from the EN that can best meet their needs (DOL, 2003).

Each beneficiary of SSI and SSDI (between the ages of 18 and 64) will receive a "Ticket" in the mail from SSA. The Ticket program is voluntary and does not have to be used by recipients. However, beneficiaries who choose to use their Ticket and are actively working with an EN to reach employment related goals will not have any Medical Continuing Disability Reviews for as long as their Ticket is in active use. The Ticket to Work program is being implemented across the nation in three phases. Currently the first group of states and part of the second group are actively implementing the Ticket to Work program. The third Groups of states will begin implementation in the fall of 2003. The Ticket to Work website at http://www.ssa.gov/work/Ticket/ticket_info.html can provide information on the status of each state. For transition students in rural areas, the Ticket to Work promises to offer access to additional agencies that have a vested interest in ensuring that employment is obtained and maintained since payment to the ENs is based on the individual moving off benefits (DOL, 2003).

Protection and Advocacy

The Social Security Administration provides funding to each of the designated Protection and Advocacy (P&A) systems in each of the fifty States, the District of Columbia, and the U.S. Territories to administer the Protection and Advocacy for Beneficiaries of Social Security (PABSS) program. The PABSS program in each state provides free of charge the following services: (1) reviews complaints against an employer network or other service provider that assists person returning to work; (2) offers information and advice about vocational rehabilitation and employment services, (3) makes available information about SSA's work incentives and how states are implementing them; (4) provides consultation and legal representation to protect individual rights in the effort to secure or regain employment; (5) assists individuals to understand and advocate for their rights; and (6) addresses problems concerning individual work plans under the Ticket to Work program (SSA, 2002).

Existing Work Incentives

In addition to these new work incentives, there are numerous existing SSA work incentives that are useful in providing a safety net when SSI/SSDI beneficiaries are employed and may lose their benefits. Several of those most relevant to students in transition are described briefly in the following sections.

Plan for Achieving Self Support

A Plan for Achieving Self-Support (PASS) allows an individual receiving SSI, or who is eligible to receive SSI, to put aside income and/or resources to be used for achieving a specific time-limited employment goal. The income and resources set aside for a PASS plan can be used to pay for a variety of services and items that would allow an individual to accomplish their employment goal including education, vocational training, and expenses incurred in starting a business. Using a PASS plan can actually help individuals maintain their SSI eligibility and even increase their SSI payment as the income and resources set aside in the plan are not counted when SSA figures an individual's monthly income to determine their SSI payment. There are several specific criteria that must be met

in order for a PASS plan to be *approved by SSA* and it is strongly recommended to check with SSA regarding the exact requirements. (SSA, 2002)

PASS plans are an often underutilized work incentive in many states although they have significant potential for helping transition students reach employment goals that may require some additional training or resources.

Individuals should receive assistance in writing a PASS plan from someone who has experience in writing these plans and is familiar with the SSA requirements.

Student Earned Income Exclusion

The Student Earned Income Exclusion (SEIE) is available for individuals receiving SSI who are under the age of 22, not married, not head of household, and regularly attending school. SEIE allow these qualified individuals to exclude up to \$1320 of their earned income a month (maximum \$5,340 per year) from the amount of income used to determine their SSI payment. (Amounts given are for 2002; amounts are adjusted yearly.)

"Regularly attending school" is defined as follows by SSA: (1) in a college or university for at least 8 hours a week; or (2) in grades 7-12 for at least 12 hours a week; or (3) in a training course to prepare for employment for at least 12 hours a week (15 hours a week if the course involves shop practice); or (4) if home taught because of a disability, individuals may be considered regularly attending school by: studying a course or courses given by a school (grades 7-12), college, university or government agency; and having a home visitor or tutor who directs the study (SSA, 2002, p. 44).

The SEIE is an important incentive for transition aged student to consider because it allows them to gain work experience and increase their earned income while they are still in school without negatively impacting their monthly SSI payment. It also encourages students to stay in school while working because they can keep a greater share of their SSI payment than they would if they were only working.

Impairment Related Work Expense (IRWE)

Impairment Related Work Expenses (IRWE) is available to beneficiaries of both SSI and SSDI. IRWEs allow individuals to deduct the cost of certain items and services that are necessary for them to work and are directly related to their disability from their gross earnings. However, these items and services must be paid for by the individual with no expectation of reimbursement. These deductions help individuals keep their earnings below the Substantial Gainful Activity (SGA) level. The SGA is the level of earnings at which SSA begins to reduce or terminate cash benefits depending on whether an individual is receiving SSI (cash benefits reduced) or SSDI (cash benefits terminated) (SSA, 2002).

There are a wide variety of items and services that can be claimed as an IRWE, however SSA must make the final determination. In general there are certain expenses in the following categories that can be used as an IRWE: attendant care services, transportation costs, medical devices, work-related equipment and assistants, prosthesis, residential modifications, routine drugs and medical services, diagnostic procedures, non-medical appliances and devices, and other items and services such as a helper animal. Perhaps one of the most important IRWE categories for individuals in rural areas to consider pursuing involves possible deductions for transportation costs, as this is often a costly and significant barrier to work particularly in rural areas (SSA, 2002).

Subsidy

Subsidies are valuable work incentives that can help individuals increase their monthly earnings, without reducing or losing their SSI or SSDI benefits. According to SSA (2002), when an SSI or SSDI beneficiary receives "extra support on the job that results in them receiving more pay than the actual value of the services they perform" (p. 33) they are receiving a "Subsidy". Examples of situations that may constitute a "Subsidy" include: (1) receiving more supervision than other workers doing the same or similar job for the same pay; (2) having fewer or simpler tasks to complete than other workers doing the same job for the same pay; (3) having a job coach or mentor who helps perform some of an individual's work (SSA, 2002, p.33). If an individual's employer documents that the individual receives some type of subsidy while on the job, SSA will adjust the individual's countable income accordingly. For example, if an employer indicates that an individual making \$1,000 per month is subsidized 30% of the time they are at work, SSA will reduce the individual's monthly earning of \$1,000 by 30% making the

individual's countable income \$700. The countable income figure is used in the SSI program to determine the monthly payment amount; in the SSDI program it is used in deciding if the worker exceeds SGA (SSA, 2002).

Conclusion

The overall purpose of the work incentives mentioned in this article, as well as others not discussed, is to assist individuals with disabilities pursue employment opportunities that can improve their quality of life. Because of the complexity of the SSI and SSDI benefits programs, it is critical that individuals and families have an accurate understanding of the work incentives that are available. This knowledge, and the subsequent actions undertaken by the beneficiary, can significantly reduce the negative impact that increased income can have on a person's benefits. A clear understanding of the possible programs and work incentives to support students in transition is important in any setting, but it may take a concerted effort for those living in rural areas to make and maintain connections with the agencies and providers that have the most up-to-date knowledge and information regarding these programs. It is important then for rural school districts to assist transition students and their families in obtaining and including the most current and accurate information regarding work incentives as part of the transition planning process. To accomplish this, rural school districts may wish to assign an individual within the school to act as a liaison between transition students and their families and the state Benefits Planning Assistance and Outreach program, local SSA representatives, Protection and Advocacy program, the Medicaid Policy Specialist for the state, etc. As mentioned previously several states are currently working to formalize the way that benefits planning (the key to using work incentives effectively) are incorporated into the transition planning process and rural school districts can and should play an important role in developing an effective mechanism for this. Parents of transition students also have an important role in advocating for the incorporation of benefits planning into the transition planning process in a meaningful way.

It is essential as school personnel who work with transition students receiving SSI/SSDI to understand that there does not have to be an "either or" situation when considering working and receiving benefits. Many of the work incentives discussed previously can be used to assist individuals to work and still maintain the safety net of SSA and Medicaid benefits. Although SSA is striving to encourage people to work and gradually not rely on benefits, those who realistically need to maintain their benefits to supplement their earned income can use work incentives to try working without risking losing vital supports.

Involving schools and transition personnel in helping individuals and families understand available work incentives is a natural fit, as students in this age range are perhaps the most likely group of SSA beneficiaries to make the transition to work and fully utilize the new and existing work incentives. Beneficiaries this age are surrounded by peers that are preparing to enter the workforce or further their education in preparation for work. This creates a natural expectation that students with disabilities should also plan on being employed. Because of the rich and dynamic environment of schools and the power of peer expectations, transition students have a greater desire and motivation to experiment with work than older SSA beneficiaries who have not worked for many years. Providing these students and their families with information about and access to work incentives during the transitions period can support them in making informed decisions that will lead to successful work experiences and subsequently the chance to experience the many benefits of work.

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